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**Conference or Workshop Item**

**Title:** Ascertaining the views of individuals with ASD using structure and visual supports

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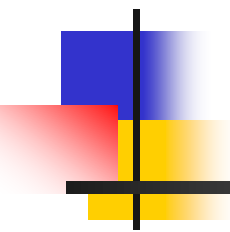
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# Ascertaining the views of individuals with ASD using structure and visual supports



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Northamptonshire County Council



# Content of this workshop

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- Look at some of the problems in getting the views of children on the autism spectrum
- Talk about two in-depth research studies carried out
- Identify what helps
- Give you the chance to think about how you can use this information in your work



# Ascertaining views of disabled children and adults

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- Required across educational and social care settings, e.g.
  - Code of Practice on the Identification + Assessment of Special Educational Needs 2002
  - Valuing People (2001)
  - Aiming High for Disabled Children (2007)



# Growing body of literature on consultation

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But...

- emphasis largely upon values + principles
- tendency to consider 'disabled children' as homogeneous group.

As a result:

- bias towards those with whom consultation easiest...not those with ASD

# Tools for consultation



- Off-the shelf resources and toolkits are available.
- But they may be inappropriate/will almost certainly need to be adapted and individualised





# Number of helpful studies

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- Germain – ‘Talking Mats’ approach
- Taylor – Involving children with MSI in person-centred planning
- Ware - PMLD



# What about ASD?

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Autistic spectrum disorders - 3 main features

- impaired **social** interaction
- **communication** impairments
- **restricted** range of interests + activities

These impairments inevitably affect our ability to effectively ascertain their views





# The research

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2 studies

- a) Classroom-based consultation study (Preece, 2002)
- b) Consultation in family home (Preece and Jordan, 2010)

Research carried out with children and young people,  
but applicable across children and adults



# Classroom-based study - focus

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- Child's experience of short breaks (respite care)
  - child's level of consultation + involvement
  - activities available
  - quality of care
  - enjoyment



# Classroom-based study - data collection: multiple methods

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- Semi-structured interviews (parents + teachers) pre-consultation
- Field notes of observation (short breaks unit + school)
- Results of consultation sessions (notes, tape)
- Teacher's field notes from short breaks unit
- Semi-structured interviews (with teachers) post-consultation + residential workers
- Documentary evidence: daily notes, files



# Classroom-based study

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- Consultation carried out by class teachers
- Research sample – 3 children, all of whom attended short breaks
  - A (12) Attends ASD unit in SLD school
  - B (7) ASD unit in Lower School
  - C (14) ASD unit in MLD school



# Classroom-based study - How did the teachers carry out the consultation?

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- A: observation visits to short breaks provider
- B: 'consultation' as part of schedule: visually organised tasks (at 1:1) structured conversation with visual prompts (quiet area)
- C: structured conversation at question time (-/+ photos)



# Home-based study - focus

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- Factors associated with why families used or didn't use short breaks (respite care)
- Consultation undertaken with mothers, fathers, siblings and children with ASD (14 families, 44 interviews) – users and non-users of short breaks
- Children with ASD –
  - Family life
  - Likes and dislikes
  - 'Respite care' / professionals
  - Wishes



# Home-based study - data collection: multiple methods

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- Semi-structured interviews with mothers, fathers, siblings and children with ASD
- Field notes of observation (short breaks providers and in the child's home)
- Semi-structured interviews with short breaks providers
- Documentary evidence: daily notes, files, social workers' assessments



# Home-based study

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- Consultation carried out by researcher
- Research sample – 14 children, aged 7-18
  - 2 x Asperger Syndrome
  - 1 x Semantic Pragmatic Disorder
  - 6 x ASD
  - 2 x Autism
  - 3 x SLD/ASD
- Education settings – schools for children with moderate>severe learning difficulties (10); FE college (1); mainstream (2); special unit in mainstream secondary school (1)





# Home-based study - How did I carry out the consultation?

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- 2 children with SLD/ASD – could not give consent therefore observed only (in family home & short breaks setting)
- the remaining 12 children – in family home
  - Initial visit – whole family together (meeting + planning session)
  - Second visit: 5 children interviewed alone, 7 with at least one parent present
- 3 children – no visual supports (parental decision)



# How did characteristics of ASD impact on consultation process? (1)

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Major issues:

- Problems regarding social interaction
  - Social anxiety
  - Aloofness
  - Problems concerning emotional responses to situations/using these to evaluate events
  - Problems concerning contexts



# How did characteristics of ASD impact on consultation process? (2)

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- Problems regarding communication
  - Limited / idiosyncratic language use
  - Poor initiation skills
  - Cue-dependence
  - Extended processing time
  - Distress at communicating
  - Phenomenon of recency
  - Echolalia



# How did characteristics of ASD impact on consultation process? (3)

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- Impairments of imagination/need for routine / resistance to change
  - Poor autobiographical episodic memory
  - Poor autobiographical episodic future thinking (imagining future/hopes/wishes)  
(see Sophie Lind, *Autism*, 2010)
  - Overselectivity
  - Dislike of change
  - Need for concreteness



# Other factors impacting on the process

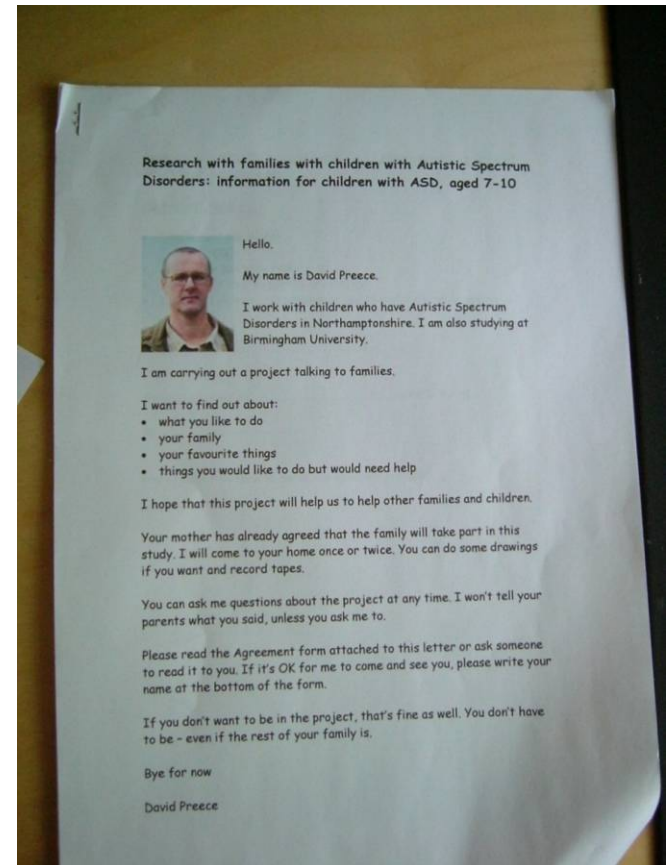
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- Parents/carers butting in – due to processing issues / habit
- Interviewer rephrasing
- Acquiescence to adults/carers
  - Agreeing with carers
  - Trying to give the 'right' answer

# What was helpful ?

## 1. Presenting information visually

- Letting the children know, in advance, who I was what I wanted to know, and why
- All children in home-based study had letter with my photo, explaining the research
- Letters differentiated for younger/older children



# What was helpful ?

## 1. Presenting information visually

- This photo was e.g. put on children's schedules
- If child could not read, parents asked to communicate information to child

NB. Meant I had to keep same haircut etc. for period of interviews!



# What was helpful ?

## 2. Spending time together before consultation

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- In classroom study, teachers already knew children
- Home-based study: initial visit – researcher spent time with child, in place interview would occur, engaging with child (e.g. playing a game, building a Lego tower, talking about child's interests)





# What was helpful ?

## 3. Giving questions visually in advance

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- At first visit, left parents, siblings and children with ASD with list of questions I'd be asking. For children with ASD, this was
  - My family
  - Things I like
  - Things I don't like
  - 'Respite care' and social workers
  - Wishes
- Some children brought their own list (of issues + answers) to the interview



# What was helpful?

## 4. Keep timescales short

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- In both studies, timescales were kept short
- In the home-based study, second interviews were carried out within 2 weeks of the initial visit
- Use e.g. visual calendars to maintain child's awareness + interest



# What was helpful ?

## 5. Using photos as supports

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- At first visit, identified (with parent(s) + child the places, people and activities I'd need to photograph
- For 11 interviews with visual supports, used over 200 photos
  - NB Issues about male researcher taking photos of children's play areas, etc
- BUT...Be aware of potentially limiting impact of visual supports

# Photographs to support interview process



# What was helpful?

## 6. Asking questions visually

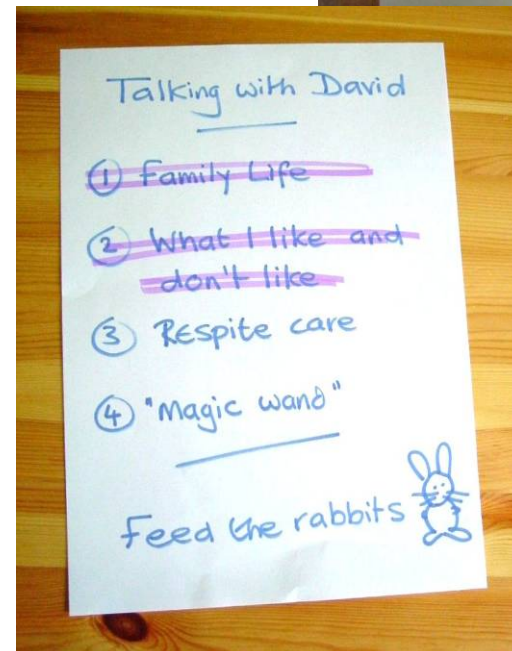
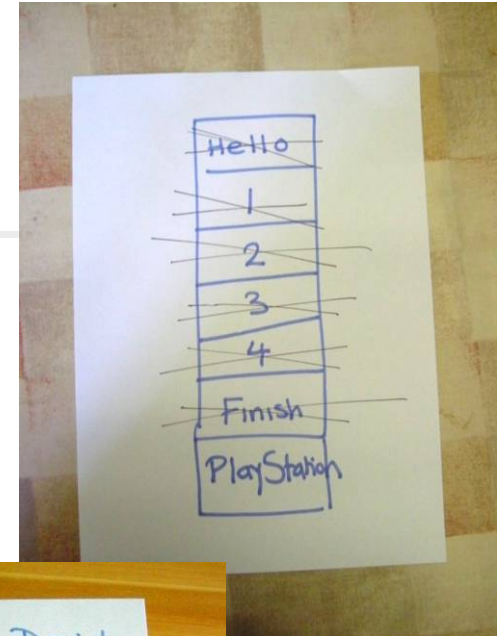
- Individualised tasks
- Used to identify preferred (and disliked) activities
- Child physically manipulated the photos
- Repeating task enabled verification



# What was helpful?

## 7. Using work systems

- Enabled the children to keep track of the process
- Let them know a preferred activity would follow
- The children manipulated the work system
- Easy questions first, finished on preferred activity



# What was helpful?

## 8. Addressing child's experience

- Schedule cards helped **some** children discuss associated activities
- Visual supports helped them remember what they have done
- Can't make assumptions about what child views as important







# What was helpful?

## 9. Tape recording interviews

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- Enabled interviewers in both studies to 'listen on all channels'
- Taping child's responses meant they could have a hard copy of what they said
- Letting children manipulate tape recorder made them active participants in process
- Go with the child's interests – I recorded children singing, playing instruments, talking to rabbits + and doing their fitness regimes



# What was helpful?

## 10. Use of proxies

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- Observation
  - by or checked out with someone who knows the individual with
  - to a structured checklist (answering the questions)
- Parental/carer support
  - Positives – support, comfort, translation
  - Negatives – acquiescence, control
- NB Triangulation essential



# What was helpful?

## 11. Triangulating data

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- Using multiple sources of information
- 'Triangulating' responses with people who knew the children helped clarify, e.g.
  - when individual's response was factually correct or incorrect
- Also helpful in trying to identify **reason** for factually incorrect responses

# What was helpful?

## 12. Individualisation

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- In both studies, no two interviews with children with ASD were the same
- But...time- and resource-consuming: home-based study took:
  - 4 months to complete consultation process
  - Over 80,000 words of transcript, 3 months to transcribe
  - 5 months to code before analysis
- No 'one size fits all approach'



# Five Outcomes Files

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- Used in residential services for children
- Portfolio of evidence based on Every Child Matter Five Outcomes
- Evidences likes, dislikes, activities, key issues – positive and negative
- Can act as proxy for child in review

# Five Outcomes File



choosing DVD - Dec '2008:



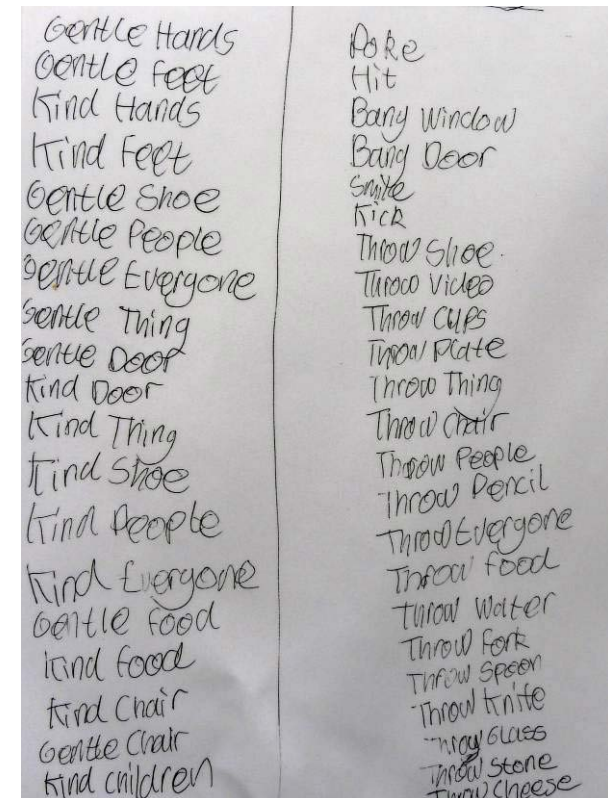
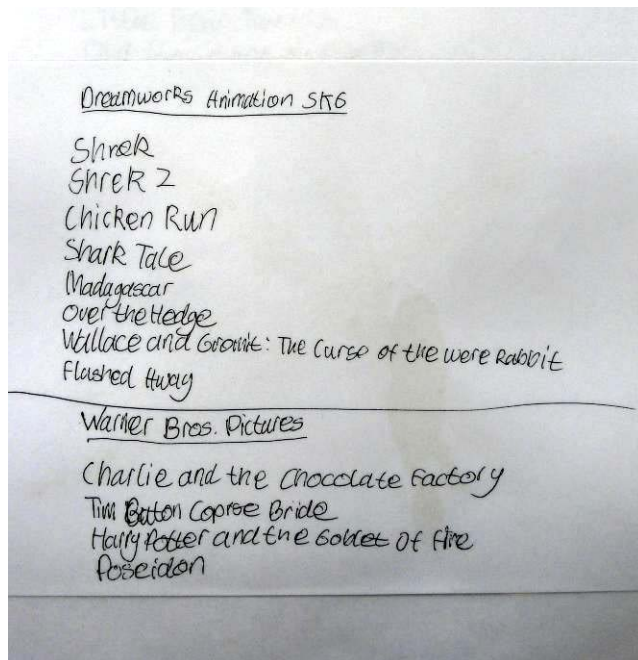
Making Cakes April 2009.



Sensory play with cornflour  
April 2009.

# The child's words

Harry could not cope with attending his reviews, but wrote down his likes and positive + negative feelings/behaviours





# Ascertaining the views of these children

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- Time-consuming
- Challenging
- Thought-provoking
  
- Important
- Valuable
- Potentially life-changing



# References

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- Preece, D. (2002) Consultation with children with autistic spectrum disorders about their experience of short-term residential care, *British Journal of Learning Disabilities*, 30, 97-104.
- Preece, D. & Jordan R. (2010) Obtaining the views of children and young people with autism spectrum disorders about their experience of daily life and social care support, *British Journal of Learning Disabilities*, 38, 10-20.